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At Risk for Huntington's Disease

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## Faith in each other: sticking together through the challenges of Huntington's disease

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# At Risk for Huntington's Disease

*HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.*


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## About Me

 [GENE VERITAS](#)

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## HD Links

[Huntington's Disease Society of America](#)

SATURDAY, FEBRUARY 03, 2018

## Faith in each other: sticking together through the challenges of Huntington's disease

*This article is dedicated to my lovely wife Regina and to HD caregivers.*

In 2017 my wife Regina and I marked 25 years of marriage with several celebrations, including a May dinner in Rome before meeting Pope Francis at [#HDdenomomore](#) and then at one of our favorite San Diego restaurants on our anniversary, December 8.

Throughout last year, I relished the many triumphs of our life together: establishing successful careers, building important friendships, and raising our daughter Bianca, who will graduate from high school in June.

I have also reflected on how Regina and I have confronted the ordeals of Huntington's disease, the debilitating, genetic neurological disorder that [took my mother's life](#) twelve years ago this month. Because I too carry the HD gene, I will inevitably develop symptoms.

Last year, former San Diego Chargers PR director Bill Johnston exemplified the commitment to caregiving when, after 38 years with the team, he [skipped its transfer](#) to Los Angeles to keep his wife Ramona in an [award-winning HD care facility](#).

"He didn't run away from his marriage vows," HD community member [Dave Elliott](#) reacted to the news in a Facebook comment. In HD families, those vows imply a heightened commitment.



[International Huntington Association](#)  
[Huntington's Disease Drug Works](#)  
[Huntington's Disease Lighthouse](#)  
[Hereditary Disease Foundation](#)  
[Huntington's Disease Advocacy Center](#)  
[Thomas Cellini Huntington's Foundation](#)  
[HDSA Orange County \(CA\) Affiliate](#)  
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[Earth Source CoQ10, Inc.](#)

## HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)  
[Angela F.: Surviving Huntington's?](#)  
[Heather's Huntington's Disease Page](#)



*Gene Veritas (aka Kenneth P. Serbin) and Regina Serbin at the Vatican Museums, with St. Peter's Basilica in the background, Rome, May 2017 (photo by Bianca Serbin)*

### Avoiding the HD shipwreck

Regina and I have faced the challenges of HD *together*.

The day after Christmas 1995, we received the terrible news that my mother had HD, that I had a 50-50 chance of inheriting the genetic defect, and that the children we planned for also faced a risk.

Many relationships shipwreck upon receiving such news ([click here](#) to read more).

However, Regina stood firmly by my side. One night, as I lay beside her gripped with fear, she hugged me tightly.

In 1999, Regina sat by my side as a geneticist revealed that I had tested positive for the HD gene.

Seven months later, we shared a tremendous sense of relief with the news that the baby in her womb, our daughter Bianca, had tested negative.

In 2011, Regina sat in the front row as I delivered the [keynote address](#) at the “Super Bowl” of HD research, the Sixth Annual HD Therapeutics Conference, sponsored by [CHDI Foundation, Inc.](#)

Each day, Regina lives with the fear that she could lose me to HD. Like my “HD warrior” father, who cared for my mother daily for more than a decade, she faces the prospect of watching (and tending) to my slow deterioration and loss of self.

However, not once has she blinked in her commitment.

With faith in each other, and also in the Creator, we have [stared down the lion of HD](#). Striding side-by-side in annual Team Hope Walks, we yearn for an effective



treatment.

### A healthy relationship might delay onset

Like any long-term relationship, ours has had its ups and downs. Sometimes our different cultural backgrounds (Regina's from Brazil) have led to disagreements. Overall, though, we have come to accept and appreciate each other's foibles.



*Ken and Regina in front of the Sugar Loaf Mountain in Rio de Janeiro, 1991 (family photo)*

We've built a united front in running the household, helping Bianca prepare for college, and strengthening the family finances, preparing for the likelihood of my disability.

Whereas my mother's HD symptoms started in her late 40s, at 58 I have fortunately avoided HD onset.

Scientists are still seeking to explain the differences in onset in people with identical HD mutations like my mother and me. I've strived to lead a healthy life, as I've chronicled in this blog.

Though the data from studies is complex, science suggests that healthy relationships can help promote overall health.







I firmly believe that I remain asymptomatic in good part because of Regina's love and support, and because of our shared mission to build a family and raise a thriving child, soon to turn 18.

### Treasuring my family

In our frenetic society, and as my aging seems to make life move faster, it becomes easy to take Regina for granted in our daily routines.

I feel a deep need to stop time and savor every moment with Regina and Bianca.

As I've pondered the deeper meaning of our marital commitment, I've focused on what's essential: treasuring them fully.

Posted by [Gene Veritas](#) at 9:59 PM      

Labels: [25th anniversary](#) , [Bill Johnston](#) , [caregivers](#) , [commitment](#) , [family](#) , [gene carrier](#) , [Gene Veritas](#) , [genetic defect](#) , [Huntington's disease](#) , [Kenneth P. Serbin](#) ,

[love](#) , [marriage vows](#) , [mother](#) , [onset](#) , [Regina Serbin](#) , [symptoms](#)

3 comments:



**Kevin said...**

Very nice Ken.

11:06 PM, February 03, 2018



**Unknown said...**

Thanks for writing and sharing this. I too have a wonderful wife who stands by me in our HD journey. I do want to share your story with others as I know there are many that struggle with this. Sometimes they seek divorce for their own safety... and others because of how difficult it may be to be a caregiver. Even when you can't be a caregiver, and many aren't able, please try to honor your vows. My prayer is for HD couples to "honor your vows" unless your or your children's safety is not possible. Respectfully, Dave and Vicky Elliott

4:10 PM, February 04, 2018

**Akila Ramanathan said...**

Very lovely and a great example. Congratulations! God bless and protect you and your family Mr.Ken

10:14 PM, February 20, 2018

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